First Steps

UTS TRAINING TIMES

Volume 8 Issue 1 February 2012

Etc.....

- Due to cost and paper reduction efforts at the State, the recently awarded UTS Programmatic Training grant prohibits printing and mailing the *Training Times.* From this point forward, the *Training Times* will only be available as an electronic publication. If you prefer reading a paper copy of the *Training Times*, you may download and print a personal copy. There is no change in the *Training Times* assessment process. Providers must pay their annual training fee to access the *Training Times* assessment online.

- The credentialing process can be confusing. Credential clarifications and reminder are included on page 13. Make sure you refer to the most current Personnel Guideline. The most current edition is located at: http://www.eikids.com/in/matrix/docs/pdfs/First_Steps_Personnel_GuideRevised_12-2010.pdf

- UTS-ProKids is working with several entities to bring national speakers to Indianapolis for training. These include Indiana Association for the Education of Young Children held April 26-28, 2012; The Institute for Strengthening Families held April 16-18, 2012; and the Infant Toddler Specialists of Indiana conference held August 14 & 15, 2012. Providers may use any of these approved conferences as FSCT. You will need to pay the nominal registration fee and submit a FSCT form to UTS. See the UTS website for additional information.

- Just a reminder - Daylight Savings Time begins at 2:00AM on Sunday, March 13, 2012. Don't forget to Spring Forward.

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INDIANA'S UNIFIED TRAINING SYSTEM

"Creating Learning Opportunities for Families and Providers Supporting Young Children"

First Steps Enrollment and Credential Training Requirements

Provider Level - New	Training for Enrollment	Training for Initial Credential
Service Coordinator (Intake and Ongoing) New to First Steps December 2007 and after	SC 101—SC Modules (self-study)	SC 102 within 3-6 months of employment date SC 103 within 6-9 months of employment date Quarterly (4) - Training Times Assessment (self-study) First Steps Core Training—one course per credential year (self study or on-site) 15 points for initial credential
Direct Service Provider (new to First Steps December 2007 and after)	First Steps Orientation or DSP 101—Provider Orientation Course (self-study)	DSP 102 - 1/2 day within 3-6 months of enrollment (on-site) DSP 103 - 1/2 day within 6-12 months of enrollment (on-site) Quarterly (4) - Training Times Assessment (self-study) First Steps Core Training—one course per credential year (self study or on-site) 10 or 15 points for initial credential
Provider Level - Credentialed	**Training for Enrollment**	**Training for Annual Credential**
Service Coordinator (Intake or Ongoing who has completed initial credential)	SC Orientation and Service Coordination Level 1 or SC 101 – SC Modules (self-study)	Quarterly (4) - Training Times Assessment (self-study) First Steps Core Training - one course per credential year (self study or on-site) 3 points for annual re-credential
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Attention: New Providers and Service/Intake Coordinators

The Bureau of Child Development Services requires all providers and service coordinators to complete the quarterly *Training Times* assessment as part of your mandatory training requirements for credentialing.

New providers must establish an account on the UTS website (**http://www.utsprokids.org**) to register for UTS trainings. Obtaining an account is easy.

1. Click the Account Login in the upper right hand corner.
2. On the login page click on Create One Here
3. Enter your information (note that UTS Training Times is mailed to your primary address—you are encouraged to use your home address, especially if it is difficult to get personal mail at your workplace, e.g. hospital system). UTS does not give any of your training profile information to anyone outside of First Steps. The BCDS and UTS will periodically send you email updates regarding First Steps.
4. When all information has been entered click the Update Information.
5. Register for your annual training fee.
6. Once your payment has been posted, you can take the Training Times assessment, under My Quizzes.
7. If you have questions or encounter problems email Janice in the UTS Connect office at: **registration@utsprokids.org**

Indiana First Steps
UTS Training Times
Ann Ruhmkorff, Editor
Tamara Hardin, ProKids Executive Director
Renee Jarboe, Training Manager
Betsy Ray, Training Coordinator
Mindy Dunn, Field Trainer
Janice Sams, Administrative Assistant

Published quarterly by Indiana's Unified Training System (UTS) - Programmatic Training at ProKids, Inc. 6923 Hillsdale Ct. Indianapolis, IN 46250. Indiana's Unified Training System (UTS) is funded through a grant from Indiana First Steps, Bureau of Child Development Services, Division of Developmental Disability and Rehabilitative Services, FSSA. Subscription fee is included as a part of the annual training fee for enrolled First Steps providers. Copies may be downloaded from the UTS ProKids web page.

Web Address: http://www.utsprokids.org

Email: Training questions training@utsprokids.org

Registration questions: registration@utsprokids.org

Service Coordinator Training Dates for 2011-12**

Service Coordination 102: All service coordinators must enroll and complete SC 102 3- 6 months after employment date. If you are unable to adhere to this timeline, you must request a training waiver. Email your request to training@utsprokids.org.

Tuesdays at ProKids, Inc. Indianapolis from 9-4pm
2/14/12 5/8/12 8/14/12

Service Coordination 103: All service coordinators must complete SC103 6-9 months after employment date. If you are unable to adhere to this timeline, you must request a training waiver. Email your request to training@utsprokids.org.

Tuesdays at ProKids, Inc. Indianapolis from 9-4pm
3/13/12 6/12/12 9/18/12

All Service Coordinators must register online for SC 102 and SC 103 at **www.utsprokids.org** .

DSP 102 and DSP 103 New Provider Follow Up Orientation**

All newly enrolled providers must complete the DSP series 101, 102 and 103 within the first year of their enrollment. DSP 101 is required for provider enrollment. DSP 102 must be completed three to six months following the provider enrollment date and DSP 103 must be completed six to twelve months following the provider enrollment date. Completion dates for these courses must be documented on the Annual Attestation Statement. The training dates for DSP 102 & 103 are listed below. Usually these trainings are held on the first Tuesday of each month at ProKids Inc. Since there are specific timelines for completion of DSP 102 and DSP103 that allow time for experience in the First Steps System, **providers may NOT take both courses on the same day.**

DSP 102 Dates	Time	DSP 103 Dates	Time
February 7, 2012	1:00-4:00PM	February 7, 2012	9:00-12:00PM
March 6, 2012	1:00-4:00PM	March 6, 2012	9:00-12:00PM
April 10, 2012	1:00-4:00PM	April 10, 2012	9:00-12:00PM
May 1, 2012	1:00-4:00PM	May 1, 2012	9:00-12:00PM
June 5, 2012	1:00-4:00PM	June 5, 2012	9:00-12:00PM
July 10, 2012	1:00-4:00PM	July 10, 2012	9:00-12:00PM

AEPS 2-DAY Certification Course**

This course provides a 2 day, comprehensive overview of the Assessment, Evaluation and Programming System (AEPS) for Infants and Children. The AEPS is a criterion-referenced developmental assessment tool for children, birth to six years. This course is required for all ED Team members. The 2-day AEPS course may also be used as a First Steps Core Training (FSCT) for your First Steps initial or annual credential. **Cost: $75**

Feb 2 & 3, 2012 May 3 & 4, 2012 Aug 2 & 3, 2012

Additional Opportunities for Credential Points

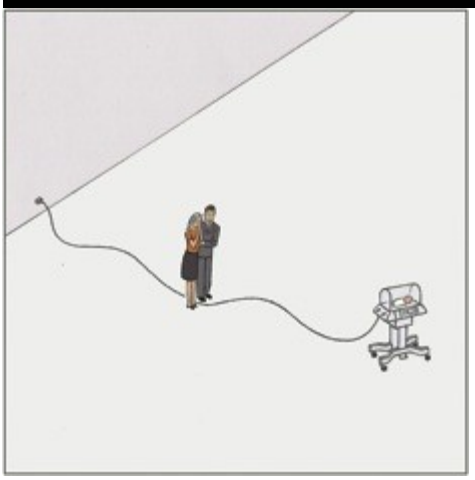
Providers may utilize trainings (on-site and self-study) and conferences outside of UTS to meet their initial or annual credential points as long as the training is related to provider or service coordinator competencies and it is relevant to infants through age 5. These may include training offered at the SPOE Provider Meetings, provider agency training related to service delivery and First Steps Core Competencies, association conferences (APTA, ASHA, etc.), hospital based conferences or grand rounds, other local, regional and national conferences, and books, videos and online training. You must keep a copy of the agenda or brochure that includes date, speakers, an agenda/content information and the time spent in the sessions you attended or a one page summary of the self-study training in your credential file. More information on credentialing can be found in the recently revised Personnel Guide at

http://www.eikids.com/in/matrix/docs/pdfs/First_Steps_Personnel_GuideRevised_12-2010.pdf

A CHILD IN TIME

New frontiers in treating premature babies.

By Jerome Groopman



Recent advances have boosted parents' hopes, but great uncertainties remain.

The entryway to the neonatal intensive-care unit in my hospital, Beth Israel Deaconess Medical Center, in Boston, is lined with photographs of children who were born prematurely. Jeremiah, delivered at twenty-four weeks, sixteen weeks early, weighed one pound six ounces. In the picture, he's a robust teen-ager, seated at a piano. Nearby is a photo of Caroline, a blond ten-year-old in a blue uniform, holding a lacrosse stick. She was born at twenty-five weeks, when her mother's placenta abruptly tore apart. Caroline has cerebral palsy, and wears an ankle-and-foot brace on her right leg, but she "is able to dance, swim, ride a two-wheel bike, play lacrosse," and "is very social," according to the caption below the photo. Across the hall is a photograph of Jackie, who's on a swing. Her mother's placenta became infected at twenty-four weeks, and she was delivered "blue," with collapsed lungs. Jackie was not expected to live through the first twenty-four hours. She's now eight years old, with a lingering lung problem, but her mother describes her as "a very beautiful girl with lots of energy. Her favorite food is everything." A few steps away, there is a drawing of a tree with leaves made of paper. On each leaf is the name of an infant who did not survive.

There are forty-eight beds in the NICU, and, on the spring day I visited with Dr. Camilia Martin, most of them were occupied. Martin is a senior neonatologist who co-wrote a textbook primer on NICU treatments, called "Neonatology Review." She told me that extremely premature infants, defined as those born before twenty-eight weeks of pregnancy, are frequently delivered by Cesarean section. At birth, their eyelids are often fused, and their ears are flat. At my hospital, four medical professionals receive each baby: an attending neonatologist, a fellow in training, a respiratory therapist, and a specialized nurse. Amniotic fluid and debris are suctioned from the baby's mouth, before he or she is wrapped in warm dry towels and placed on a heated mattress. A continuous positive airway pressure, or CPAP, mask is fitted over the nose and mouth. For many infants, the oxygen delivered by the mask is not adequate, so a tube is inserted into the trachea. Minutes after birth, replacement surfactant, a mixture of fats and proteins that looks like skim milk, is percolated into the baby's lungs. The surfactant preparation, which comes from the lungs of cows or pigs, keeps the air sacs in the lungs open. When the doctors cut the umbilical cord, they thread a thin catheter, with a bore of about one millimeter, into the umbilical vein; fluids and medications flow through it to the newborn. Another fine catheter is inserted into the umbilical artery to monitor blood pressure and levels of oxygen and carbon dioxide.

After some twenty minutes, the infant is moved to the NICU and placed in an incubator; the ones at my hospital are the Giraffe brand, which is equipped with long-necked lamps and heating elements positioned at the top of a closed plastic dome. "These babies are not prepared to enter the world," Martin said. "This technology aims to substitute for the loss of time within the mother. Their skin is not developed. You see it's translucent, without any fat underneath." Each baby had a unique sheen, a network of blood vessels starkly visible beneath the surface. "They lose a great deal of body heat and water through their skin." Inside the Giraffe, temperature and humidity are regulated to prevent hypothermia and dehydration.

"As a rule, premature babies need to stay in the NICU at least until what would be their normal gestational age," which is about forty weeks, Martin said. "And for the very early ones, born at twenty-four weeks, we add an-

other two to four weeks." Many of the babies we saw would remain in the complex support system of the NICU for between four and five months. There are similar units in most major cities and population centers; premature babies born in rural hospitals are quickly transferred. In the past few decades, the hopes and expectations of parents have been boosted by a growing number of specialized machines, procedures, and medications developed for premature infants. Beneath the picture of Caroline, the lacrosse player, is a summary of her first months of life: unable to breathe on her own, she was placed on a mechanical ventilator; an open channel between her aorta and the artery to her lungs necessitated surgery; bacteria infected her bones; fluid accumulated around her heart and prevented blood from circulating; a retinal condition that often causes blindness required laser treatment. Despite Caroline's perilous state, her parents wrote below her photograph, "We had all the confidence in the world."

On August 7, 1963, when a second son was born to President and Mrs. Kennedy at Otis Air Force Base, on Cape Cod, expectations for premature babies were limited. The boy was delivered five and a half weeks early, by Cesarean section, and weighed four pounds ten and a half ounces. Shortly after birth, he was baptized Patrick Bouvier Kennedy. The infant had difficulty breathing and was rushed by ambulance to Children's Hospital Medical Center, in Boston. He was put in a hyperbaric chamber, described by the *Times* as "one of the newest interests of medical researchers. . . . In a chamber, air under pressure allows the patient to breathe high pressure oxygen." The President flew from Washington to the hospital. But "the battle for the Kennedy baby was lost, only because medical science has not yet advanced far enough to accomplish as quickly as necessary what the body can do by itself in its own time." Baby Patrick died, thirty-nine hours and twelve minutes after his birth. The *Times* later reported, "The attending physicians certified to a diagnosis of prematurity and hyaline membrane disease . . . a lung disorder that takes the lives of about half of the 50,000 babies who contract it every year." The newspaper quoted a pediatrician who explained that the airways of such infants are coated with a thick mucous substance, "hyaline . . . that interferes with oxygen getting in the . . . lungs." The disorder, it said, "is still in many respects a scientific and therapeutic enigma."

"We hardly worry anymore about a baby like the Kennedy infant," Martin told me. "Survival at thirty-two weeks' gestational age is nearly a hundred per cent." That success is, in part, due to a discovery that was made four years before Patrick Bouvier Kennedy's birth. A young pediatrician, Mary Ellen Avery, working at the Harvard School of Public Health, found that such premature infants lacked surfactant, causing the air sacs in their lungs to collapse. Her research was largely ignored until 1980, when pediatricians in Japan gave surfactant to ten premature babies ranging between twenty-eight and thirty-three weeks. There was dramatic improvement in their chest X-rays, with nearly complete clearing of the hyaline-membrane disease just hours later; eight of the ten infants survived. But premature infants faced other challenges: there was no reliable way to regulate their body temperature or prevent fluid loss, administer intravenous nutrition or medications, treat inflamed bowels and eyes, or surgically repair blood vessels. Until recently, neonatal care involved little more than warm blankets and supplemental oxygen.

Today, the technologies of the NICU save increasing numbers of infants whose lungs, brain, gastrointestinal tract, skin, and immune system are not ready for life outside the womb. Still, babies die despite months of intensive care. And each treatment brings its own set of risks; many children who survive have neurological problems, like cerebral palsy, or severe cognitive limitations. They can be blind, deaf, or mentally retarded, or suffer with chronic lung disease. How do families and medical professionals make the agonizing decision whether to treat a premature infant at delivery and through the months in the NICU?

Worldwide, about thirteen million babies a year, nearly ten per cent of all newborns, are delivered prematurely. In the United States, the rate is higher: 12.3 per cent. Premature birth has risen by thirty-six per cent in the past quarter century, in part because of an increase in older mothers and the use of assisted reproduction, such as in-vitro fertilization, which increases the incidence of twins, triplets, and higher-order multiple births. In December, 2010, the Centers for Disease Control and Prevention noted that the birth rate for women between the ages of forty and forty-four has reached the highest level reported in more than forty years. The twinning rate rose seventy per cent between 1980 and 2004, and is

now 32.6 per thousand births, the highest on record; the rate of triplets or other multiple births climbed more than four hundred per cent from 1980 through 1998. African-American babies are one and a half times as likely as whites to be premature, which is one reason that infant mortality is so much higher among blacks than whites. Among all races, in the U.S., more than half a million infants are born prematurely every year, and another 1.1 million are "early term," born between thirty-seven and thirty-eight weeks.

The reasons for premature birth are not well understood. Sometimes the mother develops hypertension, often called preeclampsia, and blood flow to the placenta is disrupted. In other instances, the placenta fails to grow, or it abruptly detaches, as was the case with Caroline. Other women have "cervical incompetency"—the cervix dilates early and labor begins. Infections, particularly of the mother's genito-urinary tract, can induce pre-term labor as well. There are also cases in which there is no apparent precipitant.

For many years, neonatologists relied largely on gestational age in deciding whether to administer intensive care or to "redirect," which means to restrict care to palliative measures. "This was the prevailing practice, broadly held at many centers around the country," Dr. Michael O'Shea, a neonatologist at Wake Forest, who has conducted clinical studies evaluating NICU treatments, told me. Designating an age cutoff was advocated in other countries as well. In 2001, the *British Medical Journal* reported that the University Medical Centre in Leiden, Netherlands, the nation's leading facility for premature infants, "has decided in principle to stop the active intensive treatment of babies born before 25 weeks gestation because of research showing poor prognosis." Infants born earlier would be given "vigorous support" only if the parents requested it. In 2007, as techniques improved, the Dutch issued a new guideline that lowered the cutoff from twenty-five weeks to twenty-four. The appeal of a strict age-based recommendation is clear. Dr. Willem Fetter, the chairman of the Association of Paediatrics in the Netherlands, said that the new guideline offered "uniformity in our approach." Dr. Jon Tyson, of the University of Texas at Houston, concurred. "It involves a mental defense mechanism, where you believe you are making major decisions without error," he told me.

But such strictures can offer a misleading certainty when it comes to an infant's chances of survival. In 2008, the National Institute of Child Health and Human Development Neonatal Research Network, led by Tyson, published a study, in the *New England Journal of Medicine,* of 4,446 premature infants born between twenty-two and twenty-five weeks and cared for in academic medical centers. The study looked at an infant's likelihood of survival, as well as at the possibility of neurological or developmental impairment, evaluated at an age between eighteen and twenty-two months. Factors associated with a lower risk of death or disability include single rather than multiple birth, treatment of the mother with corticosteroids before delivery, being female, and higher weight. On the strength of this finding, the researchers created a Web-based algorithmic calculator, which allows a doctor to enter the premature infant's characteristics and find its chances of death and disability.

The algorithm showed neonatologists how uncertain outcomes can be for infants delivered between twenty-two and twenty-five weeks, which is currently the edge of efficacy for the NICU's capabilities. Tyson also pointed out that, even with ultrasound images of the fetus, it can be difficult to precisely determine gestational age. Frequently, couples are off by a week or more when trying to remember the time of conception. The researchers concluded, "Our findings challenge the widespread use of gestational-age thresholds alone in deciding whether to administer intensive care to extremely premature infants."

On December 4, 2004, Anna Karas, a biochemist, and her husband, Nick, a physicist, arrived at the emergency department of Beth Israel Deaconess Medical Center. (The family's names have been changed.) Both in their mid-thirties, they had been trying for almost three years to have a child. After Anna's most recent I.V.F. procedure, she had become pregnant with triplets. At week twenty, her cervix had begun to open; her obstetrician had stitched it closed and confined her to bed rest. But, two days after the twenty-fourth week, Anna's water broke. She had a Cesarean section, and a little before midnight the three babies were delivered. Martin was the attending neonatologist on call, and told me their vital statistics. The first child, a girl, weighed six hundred and sixty-five grams (about a pound and a half), and had low Apgar scores, which measure infant health at one and five

minutes after birth. A tube was inserted into her airway, and she was given surfactant and placed on a ventilator. Still, her carbon-dioxide levels climbed. She required a high-frequency oscillatory ventilation machine, which delivers up to nine hundred breaths every minute and sounds like the high-pitched knocking of a frenzied woodpecker; but even this was insufficient. Martin began to press oxygen into the baby using a hand bag, which is a bellows apparatus. “It has to be done gingerly, because if it is too forceful and you overextend the lungs you injure the infant with the first breaths,” she explained. The infant’s blood pressure fell precipitately, and saline, dopamine, and antibiotics were infused through a catheter in the umbilical vein.

Eight hours after birth, the infant’s blood oxygen was still low, her carbon-dioxide levels were high, and her blood pressure was difficult to sustain near normal levels. “She is not responding, despite everything we are doing,” Martin told the parents.

“We saw this as binary,” Nick said when we spoke about that night. “We didn’t want to be in the middle.” He and Anna felt that either the baby would survive with a reasonable chance of a good life or she should be allowed to die comfortably. Martin agreed.

The baby was detached from the ventilator, the tube removed from her throat, the catheters taken out of her umbilical artery and vein. A nurse in the NICU swaddled the baby and handed her to Anna. The infant died in her arms.

The second of the triplets was a boy, also weighing about a pound and a half. Like his sister, he was immediately intubated and placed on a ventilator, and then, as his blood pressure fell, he was given saline, dopamine, corticosteroids, antibiotics, and a blood transfusion. A chest X-ray showed pulmonary interstitial emphysema. Martin explained that the force of delivering oxygen into the lungs had caused his airway to rupture and coalesce, a sign of “how hard we were trying to get the lungs to work.” But his carbon dioxide continued to climb, as his oxygen fell. At 1:45 P.M., a little more than thirteen hours after delivery, the baby was detached from the ventilator, swaddled, and held by Anna and Nick before he died.

The third infant, a boy, had severe lung disease. “After we intubated him and gave him surfactant, we just couldn’t sustain his blood oxygen and had to put him on H.F.O.V. as well,” Martin said. His chest X-ray soon showed emphysema. His blood pressure started to fall, and he was given infusions of saline.

Nick told me that in the Greek Orthodox tradition babies are not typically named at birth. But, after their third infant survived the night, he and Anna gave him the name John.

“John developed just about every complication of prematurity,” Martin told me. His lungs were difficult to aerate, even with the H.F.O.V. ventilator. Like Caroline, he was found to have an open channel between the aorta and the pulmonary artery. Large amounts of blood that should move out from the left side of the heart were going back into his lungs, threatening to drown him. When John was five days old, he was transferred to Children’s Hospital Boston, where he underwent surgery to close the channel. He returned to the NICU at Beth Israel Deaconess Medical Center under Martin’s care; his blood pressure again fell to perilous levels, and he required infusions of dopamine. At day thirteen, an ultrasound of his head showed a hemorrhage adjacent to his cerebral ventricles, the cisterns in the brain where cerebral-spinal fluid flows. When he was a month old, he had another hemorrhage.

Two weeks later, John was given a diagnosis of retinopathy of prematurity, which can result in permanent blindness. It occurs, in part, because the high concentrations of oxygen given to premature babies are toxic to the eyes. John received repeated laser treatments to cauterize his retina.

Martin does not offer families the calculations from the Web algorithm, nor does she routinely consult them herself. “There are limitations of averages of data,” she explained. Referring to John, she said, “He is a good example of the uncertainty in neonatology, and why we prefer not to use the calculator when consulting with families.” Martin showed me how the algorithm would have applied to John. He had three negative prognostic factors: he was male, he was a triplet, and he received an incomplete course of antenatal corticosteroids before delivery. His chance of death was fifty-three per cent; of death or profound neurodevelopmental impairment seventy-one per cent; of death or moderate to severe impairment eighty-five per cent. “Every baby is unique, and every family is unique,” Martin said. “I value more the time necessary to discuss with the families various possibilities as best we know them.” Al-

though the algorithm was designed to provide estimates, often it actually reinforces the uncertainty of outcomes.

Not long after our visit to the NICU, Martin received a photograph of John. The photo shows a smiling first grader, now six and a half years old, who doesn't need glasses. He spent more than five months in intensive care, and when he was discharged one of the doctors said to his parents, "It's a miracle." Nick told me, "We answered, 'No. We knew he would make it.' "

Dr. Stella Kourembanas, the chief of the Harvard Division of Newborn Medicine at Children's Hospital Boston, whose research aims at developing novel treatments to improve lung function in premature infants, said, "You really don't know what will happen until the baby comes out." One of the drawbacks of the algorithm is that the prediction of cognitive and other neurodevelopmental abnormalities relies on testing at eighteen months. "Too often, we are focused on indicators that are too early," Kourembanas said. "The brain is very plastic; it changes with age, and this plasticity makes such predictive statements seem foolish." Early testing can frighten parents by highlighting developmental limitations that later resolve. On the other hand, it can give false reassurance when a baby tests well at eighteen months and later develops A.D.H.D. or delayed language skills, which are the two most common late-onset effects of prematurity.

Kourembanas's concern about making decisions based on short-term complications in the NICU is supported by research. Dr. Saroj Saigal and colleagues, from McMaster University, in Hamilton, Ontario, published a follow-up study, in the *Journal of the American Medical Association*, on the self-reported quality of life of extremely low-birth-weight premature infants. Each had required prolonged periods of invasive and expensive technological neonatal care. A hundred and forty-one survivors born between 1977 and 1982 were compared with a hundred and forty-five healthy normal-gestation children, all between the ages of twelve and sixteen. Proxy responses were also obtained from the parents of nine severely impaired teenagers in the premature group. Contrary to the prevailing perception, the adolescents born prematurely considered that the quality of their lives was quite high, despite the difficulties with vision, hearing, speech, and mobility reported by a quarter of the participants. As adolescents, seventy-one per cent of the premature infants rated their health-related quality of life at ninety-five per cent or better; the corresponding figure for control teenagers was seventy-three per cent. Although for a minority of those in the premature group the quality of life was much lower, "for the overwhelming majority of the [premature group], it was difficult to distinguish them from [controls] delivered at term," the study concluded. The positive perception persisted in a follow-up study, when the individuals in the study were young adults.

The uncertain and agonizing decisions made in the NICU can cause a rift between parents and caregivers. The parents of Sidney Miller, who, in 1990, was delivered at twenty-three weeks in a hospital in Houston, filed a lawsuit in which they claimed that they had not wanted any "extraordinary, heroic" measures to be taken, because of the girl's extreme prematurity. The neonatologist present at the delivery treated the infant with intubation, surfactant administration, and blood transfusions, after which she was transferred to the NICU. On the fourth day after birth, the baby had a major brain hemorrhage; ultimately, a shunt was put in to relieve the pressure. Sidney was discharged after six months, and her parents have cared for her at home ever since. She has had numerous operations to repair or replace the shunt in her brain, and she has cerebral palsy, is unable to talk or walk, and is blind and incontinent. During the trial, it was stated that with proper care Sidney Miller could live to the age of seventy.

The parents sued the hospital and its corporate owners for treating the baby at birth without their consent. In January, 1998, a jury awarded the family thirty million dollars in compensatory damages and thirteen million dollars in punitive damages. But the Texas Supreme Court reversed the decision, and found in favor of the hospital, saying that the care was appropriate given the circumstances.

After the reversal, Mark Miller wrote, "My daughter was not born disabled. The treatment protocol chosen and inflicted by the hospital, over our express objection, caused the damage, pain and disabilities Sidney endures today. The hospital's decision . . . was little more than a rescue fantasy that doomed my daughter to the very conditions we attempted to protect her from. . . . Many parents, informed of the grueling, experimental and damaging measures involved in resuscitation of these near-viable fetal-infants, make the decision to provide suppor-

tive comfort care only, without invasive high-tech heroics. It is the very kind of humane care my wife and I would want for ourselves if we were in our daughter's situation, facing excruciating treatments that would lead merely to a life of suffering."

"There are a lot of personal beliefs that each one of us brings to a specific case," Kourembanas told me. "I'm very much in favor of what the parents want. I feel that they have the burden and joy and everything that comes with raising a child. Because I'll take care of the baby in the NICU, but then I'm gone."

That approach, however, does not mean that the doctor exempts herself from the decision. "I make the recommendation, which in certain cases can be very painful," Kourembanas said. "But I feel it's far more cruel to say to the parents, 'You have *x* per cent of a chance of this complication,' and then look at them and say, as the doctor, 'I'll do whatever you want to do. Now, what do you want to do?' How are that father and mother going to go to sleep at night if they think, I killed my baby."

A study of French and American NICUs supports the idea that the doctor's recommendation whether to continue intensive care can relieve parents of guilt. The death of a baby is a devastating experience for any parent, but most of the French parents did not express the same level of grief and distress shown by their American counterparts. The explanation appeared to be that French parents whose children died had not personally made the choice not to pursue treatment. The study concluded, "American parents' tendency to express more guilt and self-blame for the decision outcome suggested their greater perceived causality may have a role."

Kourembanas told me that senior neonatologists may disagree about intensive treatments. "We are dealing with life and death, and it's not natural for a baby to die. A baby needs to live, needs to go to college, needs to have his or her own kids. Each one of us focuses on a different length of gestation. So I find that many of my colleagues would resuscitate a fetus at twenty-three weeks, if the fetus makes an effort to live."

But what constitutes an effort to live? "Babies are challenged with their first breath, so they will cry and try to breathe, they will gasp, and then some have a good heart rate," Kourembanas said. "You may say that's an effort to breathe. So some neonatologists say that any sign of life—crying, breathing, good heart rate—means the baby needs help. Others would say, 'Well, it doesn't really. It means that the baby is trying, but the baby is not able to sustain himself or herself, and technology can only delay death, or technology can actually result in injury long term.' I don't know what the right answer is, but, in the context of the data, each of us makes a determination based on our beliefs and experience."

Sheleagh Somers-Alsop, the senior clinical social worker in the NICU at my hospital, who works with families, physicians, and nurses, told me, "The pendulum swings back and forth." The "old way," with doctors delivering verdicts to families about stopping care, was authoritarian. But Somers-Alsop doesn't believe that the parents should be expected to make the decision on their own. She recalled one mother of a severely ill child who wanted to know more about continuing intensive treatment. "I would feel like I was killing my baby," the mother said. "As long as I see life in his eyes, there is a person there." Somers-Alsop speaks with each family about their decisions, and tells them that, after they leave, "it's O.K. that you revisit what happened and ask yourself, 'Did I make the right decision?' " After a baby dies, she explained, it's important for the parents to anticipate these kinds of doubts and concerns, and generally they come to terms. Yet, Somers-Alsop said, one mother whose child was severely disabled returned to the hospital over the years, ambivalent about the decision to sustain her infant, who now lived a life that she saw as one of relentless suffering, like that of Sidney Miller.

Despite advances in the care of premature infants, there is still no consensus on how to optimally treat the underdeveloped lungs, brain, and bowel. "Everything is a balance, in terms of trying to improve the function of one system, like respiration, while not injuring another, like the brain," Camilia Martin told me. Chronic lung disease, also known as bronchopulmonary dysplasia, occurs in about a quarter of all very low-birth-weight infants, and is believed to develop, in part, because of inflammation. For decades, premature infants were treated with high doses of corticosteroids to prevent inflammation in their lungs. Then a study indicated that, while babies who received steroids spent fewer days on mechanical ventilation and required less supplemental oxygen, which are clearly major benefits, they had a much

higher chance of developing abnormalities in the brain. Hospitals no longer routinely use corticosteroids. “We only give steroids when our backs are to the wall,” Martin told me.

Oxygen, long considered an unalloyed good for premature babies, has now been shown to increase the risk of severe eye damage. Research found that those who were given less oxygen were not as likely to suffer damage to the retina, with subsequent risk of blindness, but were more likely to die. As for nutrition, Martin, with Dr. Steven Freedman, a gastroenterologist, recently found that an imbalance of lipids in premature babies may increase their risk of lung, retinal, and immune disorders, and she is working to supply novel cocktails of key fats that more accurately reflect what is supplied by the pregnant mother.

Like all advanced medical science, neonatal care is extremely expensive. An estimate by the Institute of Medicine puts health-care costs for pre-term infants at more than eighteen billion dollars a year, half of the total hospital charges for newborn care in the U.S. Dr. John Zupancic, a neonatologist at my hospital and an expert in health-care economics, provided a cost-benefit analysis for the Institute of Medicine of the National Academy of Sciences. The average cost for a healthy newborn delivered at full gestational age is between a thousand and three thousand dollars; for a premature baby, it is between a hundred thousand and a hundred and fifty thousand dollars. “But for some babies it can easily be over a million dollars,” Zupancic said. “People look at what we are doing in the NICU and often there is this reaction that it’s too expensive or not worth it.” But he claims that this interpretation is misleading. With successful care in the NICU, “I can save seventy years of potential ill health,” he said, and then the economic benefit is considerable. “So this idea of drawing a line on the basis of economics should not enter into the decision-making. The costs can be astronomical for babies who have severe long-term disabilities, but, in the aggregate, the NICU can be a good investment.”

On a Sunday afternoon in March, I attended my hospital’s yearly NICU memorial service, which is held in a bright modern conference room. Nurses in scrubs sat with families that had lost infants. Parents and siblings attached paper leaves to a “memory tree” similar to the one at the entryway to the NICU. The service began with family members walking to the front of the room and placing a gladiolus, a yellow rose, or a sunflower in a vase. The parents of Nathan, who died the day after he was born, are musicians; they played the song “I Will Remember You.” The Reverend Katy Pakos Rimer, an interdenominational Protestant minister, invoked Jacob’s ladder between Heaven and earth, and said that these children “lived in the liminal space between life’s two great mysteries, birth and death.” Nancy Smith, a Jewish chaplain, recited the Kaddish, the memorial prayer for the dead. Then, as the name of each infant was read, the NICU nurses who had cared for the baby walked with the family members to the memorial tree and placed a small candle beneath it.

Some weeks after the service, I spoke with Maria Morong, a schoolteacher whose son, Mario, died in the NICU in June, 2003. It had taken three years and intrauterine insemination for Maria, at the age of thirty-three, to become pregnant. She came home on a Friday afternoon complaining of low-back pain. The discomfort increased, and at midnight she went to the hospital. Her placenta had detached from her uterus. She underwent an emergency Cesarean section. Mario was twenty-four weeks and a day, and emerged “with no respiratory effort, no movement,” according to medical records. At one minute, he had an Apgar score of 1, which indicates that an infant is close to death.

Maria told me, “The thing about the NICU is that nobody is actually prepared for it—at least, we definitely were not.” Her neonatologist told her and her husband, “I don’t know if he will make it through the first week.” They asked for a priest, who baptized and blessed him. Maria said, “I just couldn’t imagine he would die, even though people were very honest and up front about all the complications that could develop. I always thought he was going to be that kid, the one who would make it.”

“We made it clear to the people in the NICU from early on we wanted to do everything possible,” Maria told me. “But we didn’t want him to suffer. I don’t know how you balance that.” Mario underwent an operation to close an open channel between the aorta and the pulmonary artery; he also received infusions of saline and dopamine, light therapy for elevated bilirubin, blood and platelet transfusions, and antibiotics for infection with *Staphylococcus aureus*. Then he hemorrhaged into the ventri-

cle on the left side of the brain.

At each point in his care, the doctors and nurses consulted with Maria and her husband. One day, the obstetrician who delivered Mario happened to be in the NICU. Maria recalled, “She told me she could not believe that Mario was still there, a full thirty days after his birth. She had a really frank discussion with us about what kind of global problems he might have. I think her intention was just to make sure that we were really well informed.” The obstetrician emphasized that Mario had hemorrhaged in his brain, that it was unclear how long he had been without oxygen during the difficult labor and delivery. “I went home that night and I was really upset. I called early in the morning, and his nurse said, ‘You know, he just doesn’t look right today.’” Maria and her husband rushed to the hospital. Mario was retaining fluid, because his kidneys had shut down. He had developed another infection. “I just knew that day I was going to lose him,” Maria said. “They really wanted me to hold him, so I was finally able to hold him.” She and her husband took pictures with Mario in their arms. As we talked, Maria began to cry. “The nurses were really great about helping us. They let us wash him and dress him. We got his footprints and handprints and a little bit of his strawberry-blond hair. And then we just had to leave. That was the worst part.” Mario was buried next to her father.

Each year, Maria goes on a fund-raising walk with other parents who have lost a child. “I’m not really into who has the worst story, because there is always a worse story,” she told me. “But I’m so grateful for those days we had. I didn’t at the time realize how important that month was. But now I know. You don’t realize when you are pregnant how fast you start planning. You don’t realize all the dreams that you have for the child. Those days do mean something.” Two years later, Maria had a daughter, who is now seven years old, the result of “a pregnancy as normal as normal can be.” ♦

FIRST STEPS CORE TRAININGS

Online Self-Study Courses Available

1. **AEPS - An Overview**: Through this interactive self-study, participants will learn about the AEPS tool, its scoring guidelines, the importance of family reporting, and the use of the AEPS tools in the development of IFSP outcomes, strategies and activities. During the training, the participants will view a video clip of Sierra Rose while she plays at chidcare and will determine her skill level using the AEPS tools.
2. **A Family Centered Approach to Procedural Safeguards**: By learning how to view the safeguards from the family’s perspective, by learning the importance of reiterating the safeguards, and by learning the importance of using a conversational approach to present the safeguards, participants will leave this training with the tools to assure that families are fully informed in ways that support their role as the primary decision maker in the early intervention process.
3. **Providing EI Supports and Services in Everyday Routines, Activities and Places:** Learn the value of providing early intervention services in natural environments. Understand the importance of identifying a family’s everyday routines, activities, and places and identify the elements of quality service early intervention supports and services to design early intervention activities that include the features of quality supports and services. Through this interactive self-study, participants will learn the guiding principles for providing early intervention services and supports in everyday routines, activities, and places and the key features of quality early intervention supports and services.
4. **Understanding & Implementing Positive Transitions for Children & Families in Early Intervention:** looking at transition from a quality perspective as children and families move into and within the First Steps System. Quality pertains to the experience the family has during the transition and the short- and long-term effect the transition has on the children and families. Children and families’ likelihood of having quality transitions increases when their transition needs are recognized and when effective transition outcomes are written.
5. **COMING SOON - Home Visiting: Professional Boundaries and Ethics**: By participating in reflective and interactive exercises, early interventionists and provider agency personnel will increase their knowledge of professional boundaries and ethics in home-based care.
6. Also approved for FSCT are conferences co-sponsored by the UTS grant. See page 15 for details.

Spotlight on Torticollis

Each year about 1 in 250-300 infants are born with congenital muscular torticollis (CMT). The etiology of congenital muscular torticollis is unclear. Birth trauma or intrauterine malposition is considered to be the cause of damage to the sternocleidomastoid muscle in the neck. This results in a shortening or excessive contraction of the sternocleidomastoid muscle, which curtails its range of motion in both rotation and lateral bending. The head is typically tilted in lateral bending toward the affected muscle and rotated toward the opposite side (Fig.1).

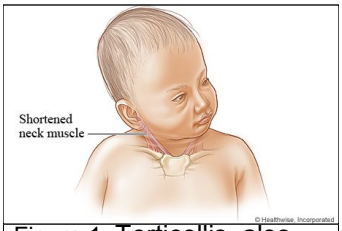


Figure 1. Torticollis, also known as "wryneck," is a condition in which one of neck muscles is shortened and the chin points to one shoulder, away from the shortened neck muscle. And the back of the head tilts toward the opposite shoulder.

Torticollis is viewed as a medical condition for which there is wide variability in clinical expression. **Therefore, the diagnosis of congenital torticollis is not considered a condition that has a high probability of resulting in a developmental delay, and children with this condition alone would not meet eligibility for First Steps.** If the primary health care provider observes that an infant or toddler is not attaining expected milestones during routine developmental surveillance, or if a parent or other primary referral source has concerns about a child's development, they should refer the child to First Steps to determine whether the child is eligible based on developmental delay. Since the AEPS may not yield a SD for an infant under 6-9 months of age, the EDT would need to provide documentation of an Informed Clinical Opinion that demonstrates a delay of 25% in one developmental domain or 20% in 2 or more developmental domains.

Most infants with CMT respond well to out-patient PT that includes parent education and training on stretching and positioning. When left untreated, the child with CMT could be at risk for developmental asymmetry, including plagiocephaly. The asymmetry may cause spinal misalignment and uneven distribution of weight over the legs, leading to the development of orthopedic problems. Therefore, early and aggressive out-patient therapy with consistent follow through in the home is imperative. The PT's focus is on play activities that incorporate active stretching, such as reaching with hands and incorporating midline and bilateral integration and active chin tuck and neck flexion/extension and rotation. With proper gains in ROM, postural symmetry and meeting gross motor milestones, children are typically discharged with clear instructions on home activities.

Parent Education is Key

Educating parents to provide gentle stretching and developmentally supportive positioning are essential to the proper progress of children with torticollis. Wedges, tiny bolsters, blanket rolls and horse-shoe shaped neck pillows are easily available and effective home positioning devices that assist in repositioning. Parents are educated on repositioning during carrying, sleeping, playing and feeding that can be easily integrated into the child's daily routine. Parents learn to incorporate active stretching techniques, for example, during every diaper change. Successful intervention for the child with torticollis is fully dependent on how successful the caregivers are in integrating treatment strategies into the child's daily routine.

- During feeding, hold the child in a way that makes him or her rotate the chin to the correct position.
- Place the crib so that the child turns his or her chin the correct way in order to see the room
- Place toys and other objects in such a way that the baby has to turn his or her head to see them and play with them.

As the infant gains strength in neck and trunk musculature, the caregivers are taught strengthening exercises that use age appropriate balance responses and transitions. The caregivers are taught infant massage and handling that will help to promote balanced, healthy tissues and somatosensory development. Parents are encouraged to look for any regression observed in this population until 3 years of age. Parents must keep in mind, however, that with gains in every motor milestone, the child may regress temporarily but should catch up as he masters the new skill.

Credential Clarifications & Reminders

The initial credential must be completed within 2 years of the provider's enrollment date. Providers must document successful completion of DSP101, 102 & 103, 2 years (8 issues) of TT quizzes and 2 First Steps Core Training (FSCTs), one for each year. Providers will need two grid pages to record all credential points. Please note that DSP 101, 102, and103 ***DO NOT*** count as a FSCT for the initial credential. CSC will contact providers when the packet is incomplete or clarification is needed. Submission of the packet alone, does not meet the recredential requirement. The credential packet must be approved by CSC. Providers will receive a letter once the credential has been reviewed and approved.

Ideally, annual credential packets should be submitted 30 days prior to your credential date. Once received, the packet will be reviewed by CSC. CSC will contact provider agencies, when a credentialing packet is incomplete or clarification is needed. If additional information is needed, the 30 days, allows the provider time to respond, without an interruption in credentialing or enrollment. A timely recredential is needed in order to remain enroll in the system.

When submitting your credentialing packet, you must provide a copy of the UTS "My Training and My Quizzes" page, showing payment of your annual training fee, completion of all four Training Times (TT) and one First Steps core training (FSCT). In addition, providers must complete additional activities such as education, training and experience, to document a full 3 points within the year. Activities counting toward your credential must be completed during the credentialing year. Therefore, if you credential is due March 15, 2012, you may only count trainings that occurred between March 16, 2011 and March 15, 2012.

The credential packet must be approved by CSC. Providers will receive a letter once the credential has been approved.

CSC may pend credentials for additional information or documentation. The provider must submit the requested documentation before the end of the month due. If the information is not received, the provider will receive a final notice letter, giving 14 days to respond or face dis-enrollment.

Providers must submit copies of their UTS profile "My Trainings" and "My Quizzes" pages to document completion of the four required TT quizzes and one FSCT.

Experience for the annual training must be in early intervention and for infants and toddlers, birth to 3 years of age. Providers need to pro-rate their experience to reflect work in other areas or with older children and adults. Providers must use the chart found in the Personnel Guidelines December 2010 page 13 to pro-rate their experience. To pro-rate experience, the provider must calculate the average hours worked per week in early intervention, birth to three. A letter from their provider agency or other documentation should be maintained in the provider's personal credential file to verify the points taken for experience.

Provider agency meetings discussing business processes, agency issues, etc. do not qualify for credential points. Provider Agency training or in-service education may count towards the credential if the topic discussed is related to the First Steps competencies and is specific to infants and toddlers. Providers should list the date, trainer name/discipline, title of the training and time/credential points for the training. Providers must maintain documentation of the training in their personal training file. This documentation must include training title, date, trainer name, and an agenda or training outline.

Provider Agencies are required to forward all communication between CSC and the Agency in regards to a provider's credential application, information requests and credential approval. Agencies must be timely in notifying providers, as the provider is at risk for dis-enrollment if they fail to response to a final warning letter.

Training Opportunities

Signing Time Workshop * With Rachel Coleman

Friday, April 27, 2012

6:30 – 8:00 p.m.

Indiana Convention Center, Hall H

100 S. Capitol Ave., Indianapolis, IN

Don't miss this rare opportunity to see Rachel Coleman, Emmy-nominated host of ***Signing Time!,*** live and in person. Rachel will use songs, signs and group interaction from the Signing Time series to teach families and children the power that comes from learning how to communicate using American Sign Language (ASL). In addition, she will tell her inspiring story of being the mom of two children with special needs. Join her for a meet and greet after the show too!

Registration: $15.00 for Individual or $25.00 for Family of 5 or less

To register, go to www.utsprokids.org
For more information contact Janice at 317-472-5602 registration@utsprokids.org

Hosted by ProKids, Inc., Down Syndrome Indiana &
The Indiana Association for the Education of Young Children

Registration is now open for the

2012 Indiana Early Childhood Conference

April 26 - 28, 2012

Indiana Convention Center ~ Indianapolis

Hurry - Early Registration Discount ends February 17, 2012

Preliminary Program:

http://www.iaeyc.org/LinkClick.aspx?fileticket=1w0%2f1Xx%2flXk%3d&tabid=814&language=en-US

FSCT Approved!

Washington Learning Systems is making available, at no cost, parent-child early literacy activities in English, Spanish, Vietnamese, Mandarin, Somali, Burmese and Russian.

Language and early literacy activities: Free and Reproducible

Developed by Angela Notari-Syverson, Ph.D, and Judy Challoner, M.S.

These materials include home and community activities for adults and young children (birth to five) that encourage early language and literacy development. They are appropriate for children with disabilities as well as children who are developing typically. Each of the activities includes an activity description, and hints for making the activity fun and developmentally appropriate. An activity checklist helps parents and caregivers notice their children's skills, and also cues adults to examine and grow their own interactions with children. The materials are made available by Angela Notari-Syverson and colleagues, and may be copied and distributed as long as they are not sold.

To download materials go to http://www.walearning.com and click on the button that says "Literacy Resources" on the home page. You will need to create a logon account using your email address and a password.

The development of these materials was supported in part by Grant H324M020084 from the U.S. Department of Education, Office of Special Education Programs, and by funding from Washington Learning Systems.

SAVE THE DATE

FSCT Approved

THE Institute for Strengthening Families Conference

The Institute for Strengthening Families

April 16-18, 2012

Indianapolis, IN

http://www.theinstituteforfamilies.org/

Happy New Year!

As a small gift to you to help ring in 2012 click on the image *(above)* to view a free video clip and PDF of the most important exercise you can do with your baby, **'Tummy Time'**.

We wish you and your little ones all the best in 2012.

Enjoy, - The Team at Baby Builders

Plan to attend the 8th Annual ITSI Institute

August 14 & 15, 2012

Ft. Benjamin Harrison, Indianapolis, IN

Keynotes: **Joye Newman**, co-author of *Growing an In-Sync Child* and
Ron Lally from West Ed Program for Infants and Toddlers

FSCT Approved!

FETAL ALCOHOL SYNDROME

Indiana First Steps hopes you will listen to and share the audio cast, "**A View into Fetal Alcohol Syndrome - a Father's Perspective**". This podcast is a must for *any* parent of a child with special needs, educators, and professionals in the disability field. In this powerful interview, Michelle Fisher, host of "A View from My Window," talks with Craig Peterson, father of four children impacted by fetal alcohol syndrome. Craig talks not only of what he has learned about the impact of this 100% preventable condition, but also shares information helpful to any parent who has a child with special needs, "(I'm) really trying to talk about the gifts that children bring, how do we work with their strengths, how do we never lose our vision of what can be, always clinging to that faith that we have or that we have to find and making a better life for these children." Craig is currently working on a book about his experience, *Adopting Faith: A Father's Unconditional Love.*

Click to listen to the podcast: http://www.arcind.org/upload/media/A_View_into_Fetal_Alcohol_Syndrome.mp3

You can find all of Michelle's shows, produced by The Arc of Indiana, at "A View from My Window."

Facts about FASDs

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems and problems with behavior and learning. Often, a person with an FASD has a mix of these problems.

Cause and Prevention

FASDs are caused by a woman drinking alcohol during pregnancy. There is no known amount of alcohol that is safe to drink while pregnant. There is also no safe time to drink during pregnancy and no safe kind of alcohol to drink while pregnant.

To prevent FASDs, a woman should not drink alcohol while she is pregnant, or even when she might get pregnant. This is because a woman could get pregnant and not know for several weeks or more. In the United States, half of pregnancies are unplanned.

Signs and Symptoms

FASDs refer to the whole range of effects that can happen to a person whose mother drank alcohol during pregnancy. These conditions can affect each person in different ways, and can range from mild to severe. A person with an FASD might have:

- Abnormal facial features, such as a smooth ridge between the nose and upper lip (this ridge is called the philtrum)
- Small head size
- Shorter-than-average height
- Low body weight
- Poor coordination
- Hyperactive behavior
- Difficulty paying attention
- Poor memory
- Difficulty in school (especially with math)
- Learning disabilities
- Speech and language delays
- Intellectual disability or low IQ
- Poor reasoning and judgment skills
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with the heart, kidneys, or bones

Guidelines for Diagnosing FAS

Deciding if a child has FAS takes several steps. There is no one test to diagnose FAS, and many other disorders can have similar symptoms. Following is an overview of the diagnostic guidelines for FAS. For more detail, see the full text Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis for healthcare providers and other clinicians. These criteria have been simplified for a general audience. They are listed here for information purposes and should be used only by trained health care professionals to diagnose or treat FAS.

Summary: Criteria for FAS Diagnosis
A diagnosis of FAS requires the presence of all three of the following findings:

- All three facial features, 1) Smooth ridge between the nose and upper lip (smooth philtrum), 2) Thin upper lip and 3) Short distance between the inner and outer corners of the eyes, giving the eyes a wide-spaced appearance.
- Growth deficits
- Central nervous system problems. A person could meet the central nervous system criteria for FAS diagnosis if there is a problem with the brain structure, even if there are no signs of functional problems.
- Confirmed alcohol use during pregnancy can strengthen the case for FAS diagnosis. Confirmed absence of alcohol exposure would rule out the FAS diagnosis. It's helpful to know whether or not the person's mother drank alcohol during pregnancy. But confirmed alcohol use during pregnancy is not needed if the child meets the other criteria.

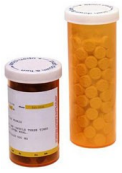
Treatments

Many types of treatments are available for people with FASDs. They can generally be broken down into five categories:

1. Medical Care
2. Medication
3. Behavior and Education Therapy
4. Parent Training

Medical Care

People with FASDs have the same health and medical needs as people without FASDs. Like everyone else, they need well-baby care, vaccinations, good nutrition, exercise, hygiene, and basic medical care. But, for people with FASDs, concerns specific to the disorder must also be monitored and addressed either by a current doctor or through referral to a specialist. The types of treatments needed will be different for each person and depend upon the person's symptoms.



Medication

No medications have been approved specifically to treat FASDs. But, several medications can help improve some of the symptoms of FASDs. For example, medication might help manage high energy levels, inability to focus, or depression. Following are some examples of medications used to treat FASD symptoms:

- **Stimulants -** This type of medication is used to treat symptoms such as hyperactivity, problems paying attention, and poor impulse control, as well as other behavior issues.
- **Antidepressants -** This type of medication is used to treat symptoms such as sad mood, loss of interest, sleep problems, school disruption, negativity, irritability, aggression, and anti-social behaviors.
- **Neuroleptics -** This type of medication is used to treat symptoms such as aggression, anxiety, and certain other behavior problems.
- **Anti-anxiety drugs -** This type of medication is used to treat symptoms of anxiety.

FAS Continued

Medications can affect each child differently. One medication might work well for one child, but not for another. To find the right treatment, the doctor might try different medications and doses. It is important to work with your child's doctor to find the treatment plan that works best for your child.

Behavior and Education Therapy

Behavior and education therapy can be an important part of treatment for children with FASDs. Although there are many different types of therapy for children with developmental disabilities, only a few have been scientifically tested specifically for children with FASDs.

Following are behavior and education therapies that have been shown to be effective for some children with FASDs:

- **Friendship training**
  Many children with FASDs have a hard time making friends, keeping friends, and socializing with others. Friendship training teaches children with FASDs how to interact with friends, how to enter a group of children already playing, how to arrange and handle in-home play dates, and how to avoid and work out conflicts. A research study found that this type of training could significantly improve children's social skills and reduce problem behaviors.[2]
- **Specialized math tutoring**
  A research study found that special teaching methods and tools can help improve math knowledge and skills in children with FASDs.[3]
- **Executive functioning training**
  This type of training teaches behavioral awareness and self-control and improves executive functioning skills, such as memory, cause and effect, reasoning, planning, and problem solving.
- **Parent-child interaction therapy**
  This type of therapy aims to improve parent-child relationships, create a positive discipline program, and reduce behavior problems in children with FASDs. Parents learn new skills from a coach. A research study found significant decrease in parent distress and child behavior problems.
- **Parenting and behavior management training**
  The behavior and learning problems that affect children with FASDs can lead to high levels of stress for the children's parents. This training can improve caregiver comfort, meet family needs, and reduce child problem behaviors.

Parent Training

Children with FASDs might not respond to the usual parenting practices. Parent training has been successful in educating parents about their child's disability and about ways to teach their child many skills and help them cope with their FASD-related symptoms. Parent training can be done in groups or with individual families. Such programs are offered by therapists or in special classes.

Although each child is unique, the following parenting tips can be helpful:[4]

- Concentrate on your child's strengths and talents
- Accept your child's limitations
- Be consistent with everything (discipline, school, behaviors)
- Use concrete language and examples
- Use stable routines that do not change daily
- Keep it simple
- Be specific-say exactly what you mean

- Structure your child's world to provide a foundation for daily living
- Use visual aides, music, and hands-on activities to help your child learn
- Use positive reinforcement often (praise, incentives)
- Supervise: friends, visits, routines
- Repeat, repeat, repeat

Families might need support from a family counselor or therapist. Parents might also benefit from local support groups, in which parents of children with FASDs can discuss concerns, ask questions, and find encouragement. Check with one of the following resources to find support in your area:

1. National and State Resource Directory from the National Organization on Fetal Alcohol Syndrome (NOFAS)

2. Family Empowerment Network (FEN) - Call 1-800-462-5254 for referrals to services

3. FASD State Systems of Care from the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence

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Information sourced from http://www.cdc.gov/ncbddd/fasd/hcp.html.

The TT Self-Assessment is due
12:00mn EDT, April 30, 2012

http://www.utsprokids.org